



A guide to developing personalised residential supports (PRS) for adults with developmental disabilities and their families

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The aim of this guide is to provide information for families, people with developmental disabilities, and service providers who want to develop high quality accommodation support that is person-centred. The guide is based on the *Personalised Residential Supports* (PRS) project. This was carried out over two and a half years and explored person-centred approaches to supported living for adults with developmental disabilities.

The study was carried out by:

- Reviewing a wide range of printed information;
- Following the stories of six adults with developmental disabilities, their families, and supporters in their living arrangements; and,
- Surveying a number of people in Australia who have much experience in developing person-centred accommodation support.

The PRS project received funding from Lotterywest, and was overseen by a group headed by the Developmental Disability Council of WA. The group included representatives from families, National Disability Services WA, and the WA Disability Services Commission.

Curtin University's Centre for Research into Disability and Society in the School of Occupational Therapy and Social Work was engaged to carry out the project.

We are very grateful to the many people who contributed to the project, particularly the people with a developmental disability, their families, and supporters who gave so freely of their stories, and the people who responded to the surveys and gave so freely of their expertise.

WHAT IS THE GUIDE ABOUT?

This guide is written for anyone who has an interest in developing a supported living arrangement for an adult with a developmental disability. The information here may also be useful for supported living arrangements for any person who has special needs.

The guide is based on the important belief that supported living arrangements should be developed around individuals and should be shaped by the needs, preferences and wishes of each person with the appropriate influence of people who are close to, and care about, that person. We have called this *personalised residential supports* (PRS). A related idea is captured by the term *person-centred supports*.

The PRS project described nine key ideas or themes that provide the foundation of personalised/person-centred supported living. This guide is based on those nine key themes. They provide important information for people who are planning a new supported living arrangement. They also provide guidance for people who are wishing to change or develop an existing supported living arrangement.



WHAT'S IN THE GUIDE?

The stories. We begin by briefly telling the stories of the six individuals who shared their stories with us.

The themes. We then describe each of the nine themes.

Some guidelines. Finally, we outline some important aspects of developing high quality, personalised residential supports for an adult with a developmental disability.

Some resources.

THE STORIES

Over periods of up to 18 months, we followed the stories of six persons with developmental disabilities in order to learn more about how personalised residential supports are established and developed.

We began by using our networks to identify a number of examples of individuals who were in, or planning, this form of residential support. From a larger group, we selected six individuals who agreed to participate in the project. These six people represented a range of different types of support and stages in the development of support. We spent time with them, with their families, and with the individuals and agencies that provided support, and we learned a lot!

Their stories are very briefly described here.

ROB'S ARRANGEMENT

Rob is a man in his late 30s who rents an inner-city townhouse along with two non-disabled co-tenants, Ben and Laura. As such, it is sometimes described as a 'co-resident model'. *Vemvane*, a non-government non-profit organisation based in Whitfords, set up this model for Rob in conjunction with his mother, Arax, 14 years ago. It has been a remarkably stable home life for Rob, with only a small handful of co-residents in that time, some of whom are still part of his friendship network.

Rob was involved at the very beginning in the selection of the first two co-residents and there has never been the need to advertise for new co-residents since. His social network has grown such that people have emerged from among his friends and contacts when needed.

Rob has what are referred to as "moderate" support needs. His needs were much greater when the arrangement was set up, but his living arrangement has been so rich and supportive that his skills and general wellbeing have developed greatly over time. His social network has grown, initially in a planned, and then in a loose informal way, to now include some close friends and many acquaintances. A host of opportunities have also arisen, such as international and interstate travel, a range of work roles, and a warm welcome at many businesses in the inner-city area.



Ben and Laura receive a part-subsidy from *Vemvane* on their rent and bills, in return for which they are basically 'there' for Rob, such as by ensuring that someone is home overnight and for the evening meal. They provide occasional day to day assistance to Rob as needed, but the relationships have grown into genuine friendships among the three who live in the townhouse. For the sake of security of tenure, the lease agreement is held by *Vemvane* on behalf of Rob. *Vemvane* provides support staff to come in for a few hours on weekdays in order to support Rob in a range of activities, and generally oversee the arrangement, albeit from a distance for the most part. Rob and Arax share a close relationship and spend time together often.

ANDREE'S ARRANGEMENT

Andree is a woman in her late 30s who leases a *HomesWest* unit in her own name in the northern suburbs of Perth. A non-profit housing service agency provides assistance in regard to matters concerning the lease. Andree's support is arranged by *My Place*, a non-government, for-profit organization. Andree's parents, Jackie and John, are very much a part of Andree's life, and have fought hard over the years for funding and services to meet Andree's needs. They are in close contact with *My Place* regarding all major aspects of Andree's living arrangement. Andree and her family have been connected with *My Place* for around ten years, and after some early unsuccessful stints in group living arrangements, she was assisted to set up in a home of her own, and has been living in her current unit for around three years.



Andree needs very considerable support in her day to day life, as areas including communication and understanding what is going on around her can be difficult, and it takes people who know her well to be able to understand her and to respond when she needs a hand. After struggling with a range of support models to suit Andree, *My Place* now provides staffing on a live-in arrangement whereby one staff member lives in Andree's unit for one week, then a second staff member lives in for the second week and so on, with the two people alternating. Periods in which there is no support available are generally covered by John and Jackie, and Andree's Nanna, who have Andree over to stay from time to time. With her lifestyle, general wellbeing, and support arrangements now settled, Andree's parents and *My Place* are looking to extend Andree's membership of the broader community, including a possible move from sheltered to open employment.

GEOFF'S ARRANGEMENT

Geoff is in his late forties and has lived with Jackie, and her husband Brad for about six years in a “host family” arrangement, in their home in a large town in the south of WA. Geoff has a significant developmental disability and spent his early years in special classes and then a day centre run by the (then) *Slow Learning Children's Group* in Perth. Following disagreements between Geoff's parents and disability services in Perth, Geoff was withdrawn from services and lived with his parents for



over 20 years. After his father died and his mother became too ill to care for Geoff, his brother Brian and sister-in-law Averil, who lived in the south of the state, decided that they wanted Geoff to live near them. Brian is Geoff's legal guardian.

They approached the *Lower Great Southern Community Living Association (CLA)* which facilitated the current arrangement. Brian also arranged for his mother to be moved to a local nursing home where he said she was well cared for. She died a couple of years ago.

Geoff needs help with some self-care activities and has had a few health problems. Jackie is the principal carer and is supported by Brad. The CLA coordinates and provides support for day activities for Geoff. In addition, Geoff participates in Jackie and Brad's social and recreational life.

Jackie and Brad thought carefully about taking on the task and spent time ensuring there were common interests between Geoff and themselves. Jackie recounted: “We had to ask (Geoff) how he felt about us. We also told him about our life to give him an idea about what we're like. Told him about our pets and hobbies. Realised we had the same interests. Camping and music. (Geoff)...is a real music lover and has music going quite often and it would be very difficult to live with people who didn't like music almost the whole time.”

He has his own room, bathroom, lounge, and television. He shares an interest in music with Jackie and her husband.

JUDE'S ARRANGEMENT

Jude is in her early fifties. She is the middle of five children of Mary and John, long-time farmers in the south of WA. At nine months, Jude began having seizures that were difficult to control and were associated with a significant developmental



disability. Jude's parents received support from their family, especially Jude's maternal grandmother, who enabled Jude's attendance at the (then) *Spastic Centre* in Perth. After about a year there, Jude returned home and the busy and demanding family and farm life meant further support was needed from the (then) *Slow Learning Children's Group* at a place called *Pelican*. At about this time, *Pyrton Training Centre* was established and Jude was provided with short stays. As Mary recalled, "...there was nowhere else for her to go other than *Claremont Mental Hospital*, and that was out of the question".

In the late 1980s, Local Area Coordination was initiated in the area, and Peter came on to the scene. His early contact with Jude's parents was challenging to all! When Peter suggested that Jude share a house in a nearby town, Mary described her initial response: "I threw him out of our house once!" Peter persevered and eventually prevailed. Mary went on to describe their early contact. "He was lovely. He was not *Pyrton*-minded. Made all sorts of suggestions that Judy might be able to do this and you'd never be able to know. I thought 'Oh my goodness! This is too much.' I don't think we were able to get our minds on the future. We were so busy with what was going on right then that we couldn't look to the future. We needed someone else to do our thinking for us."

Initially, Jude moved into a home with another woman with a disability, but that didn't work. However: "Peter was persuasive and we became convinced that he was on the right track. We liked him. He was good. It's hard for a mother who had the whole thing to accept that somebody else could do it." An arrangement was made through the *Lower Great Southern Community Living Association* for Jude to live with Kathy and her family in the nearby town and this arrangement continued for over 15 years. Mary was clear about her bottom line. "The main thing I said to Peter... was that we wanted to be sure that whoever looked after her loved her and respected her as a human being. That was very important. And that's what we got."

As Kathy's family situation changed, her sister Toni, who had been providing occasional care for Jude for about 13 years, took over. It is quite remarkable that Jude's circle of family and friends has been stable within these support arrangements for approaching 20 years.

Now Jude's needs are changing and thought is being given to a quieter life for her and providing more security by supporting her in her own home. Planning for this has been continuing for about 12 months and there is much consideration being given to ensuring continuity in her life. Mary reflected: "The big step was letting her come down here in the first place because I was sure no-one could look after my daughter as I would. I found out there are wonderful people in the world. They're special. And so we were able to let go of her and we knew she was being treated with respect and love and cared for – and it was a relief."

LISA'S ARRANGEMENT

Lisa is a woman in her mid-20s who lives alone in her own villa in the northern suburbs of Perth. Lisa owns the villa, an arrangement set up by members of her family on the passing of her mother. She maintains a strong family network, and a generally active lifestyle. Lisa looks after most aspects of her day-to-day life and receives drop-in support for a few hours each week to assist in areas such as diet, budgeting, mail, and any matters that pop up that Lisa needs a hand with. This support is arranged by *Baptistcare*, a non-government, not-for-profit service provider.



Baptistcare, through its then new entity '*Partners in Purpose*', was amongst the first providers to embrace the 'Shared Management Model', which provides a means for people with disabilities and their families to partner with a provider in the arrangement and provision of supports, in a balance to suit all parties. In Lisa's case, a *Partners in Purpose* Coordinator takes care of all of the formalities such as funding and staffing. Lisa's lifestyle is quite busy, as she is able to independently travel to and from work, the shops, to visit her aunty and so on. As with Andree, a longer term goal is for Lisa to secure a job in open employment, which could add new challenges and opportunities to a lifestyle that Lisa already enjoys.

LUKE'S ARRANGEMENT

Luke is a young man in his early 20s who currently lives in the family home with his parents, Mary and Richard. Luke needs very considerable support, such as from people who know him well and

can interpret his very limited means of communication. Although Luke is living at home, his 'arrangement' was included in the PRS project due to his parents' efforts over several years to plan and develop a personalised living arrangement for him. Hence there was a great deal to learn from them about issues including planning and parent leadership of an emerging arrangement.

Mary and Richard's journey has included contact with some people considered as international authorities on planning and community living. Their thinking and expertise has grown to the point where Luke now has a social support network in place, a *Microboard* has been established, and accommodation support funding has been secured. Crucially, Mary and Richard's ideas have grown into a strong determination that Luke should have a home and lifestyle that reflect the key themes of the PRS project. Apart from the people they have had contact with, these ideas have also been informed by first hand experiences of group living arrangements, which they conclude cannot provide the sort of life for Luke that they have in mind, and which they believe he wants and needs.

THE THEMES

The nine themes described here were drawn from a careful process of distilling the key, foundational ideas from the information we gathered in the project. They reflect the essential qualities that informed and guided the efforts of people who were intent on developing personalised residential supports (PRS) for an individual with a developmental disability.

1

POSITIVE ASSUMPTIONS

PRS arrangements are underpinned by assumptions that reflect high expectations for the person with a disability. At the heart of these assumptions is the belief that all people, regardless of the level of support they require, can live in a home of their own.

2

LEADERSHIP

PRS arrangements come about through at least one person who has a clear vision and strong ideas, and is persistent. The leadership can come from any source, including the person with a disability, family members, and service providers.

3

MY HOME

A PRS arrangement creates the person's own home. The person has a personal "stake" in their home. Their home reflects their personality and preferences. It is a place where the person does the ordinary things people do in their homes.

4

ONE PERSON AT A TIME

PRS are unique arrangements that focus on each person with a disability, with his/her "voice" being central. The arrangements are based on personal knowledge of the person and are often guided by people who know the person well – by those who care about them.

5

PLANNING

PRS arrangements require careful planning that at times may take a lot of time and effort. Planning may involve those close to the person and is based on that person's uniqueness, strengths, and needs.

6**CONTROL**

The person for whom the PRS arrangement is provided and others who are close to him/her, particularly family members, have a big influence on the arrangement. This may include direct “governance” or control by the person or the family where appropriate on various aspects of the arrangement including its planning, its development, and its implementation.

7**SUPPORT**

Support to the person in a PRS comes from many different informal and formal sources. This includes family and friends, neighbours, advocates, ordinary citizens, and paid workers through organisations. A PRS strives for a balance between formal and informal supports which are flexible and responsive to changing needs.

8**THRIVING**

PRS arrangements provide general well-being and an enhanced lifestyle, and promote the growth and development of the person. The arrangement contributes to personal growth in areas such as independence, self-determination, skills, and valued roles in the home and community.

9**SOCIAL INCLUSION**

PRS arrangements are highly individualised and thereby avoid congregating and segregating the person with a disability. There is a focus on participation and engagement in ordinary life and through personal relationships.

These themes are positive and challenging. Through the information gathered in this project, we can see that they are achievable.

SOME GUIDELINES

The nine themes provide some guidance for the planning and development of personalised residential supports. In this section we provide some key questions and principles to consider as the PRS develops. These also provide some important issues and arguments that should be discussed by the stakeholders in this process.

Do high expectations drive the process?

The standpoint here is an acknowledgment that the person does not need to “qualify” in order to live in a person-centred accommodation support arrangement. The conditions for success are focused on *how the arrangement can address the needs of the person*. Common assumptions that need to be challenged, include:

- PRS (or these principles) are not for people with high or complex support needs;
- People with a disability need to live together; and,
- A PRS is only for people who can live independently or alone.

Vemvane's CEO expressed high expectations in this way:

I think it doesn't matter what their disability, or level of disability is, or what they're like particularly. I think with patience, with the right support, I believe there are possibilities open to anyone. I really do believe that. If I didn't believe that, I wouldn't have attempted it with Rob.

Leadership is important.

Leadership was widely acknowledged and quite visible throughout the project. The qualities of leaders and leadership that were evident included:

- Willingness to put forward ideas and options that were different from prevailing views about how people with a disability could live – ideas that were challenging and possibly visionary;
- Willingness to take considered risks in order to achieve a better outcome for the person;
- Persistence and perseverance, often in the face of outright rejection or opposition; and,
- Leadership that emerged from many different sources and involved partnerships and collaborations.

A policy-maker expressed that:

Leadership and direction is critical. Also, success is likely to be better achieved when leadership is invested in a range of people so arrangements do not fail when a person can no longer take that role

Kathy spoke about the influence and persistence of leadership.

I came back to get a job as a support worker here. Peter had this philosophy that we were going to set up these individual supports – I thought it was fantastic. Everything I'd been reading and learning about...I really believed this could work.

Is it very clear that the arrangement is the person's own home?

This is an important question with many parts, each of which need to be considered as the arrangement develops. For example:

- Is the arrangement the person's home, or the home of an agency (a "service") or another person?
- What is the kind of "stake" the person has in their home? How can the concept of "ownership" apply to the arrangement?
- Does the person have the essential "freedoms" and rights in regard to their home that are culturally appropriate? For example, how are freedom of choice, movement, and expression reflected in the arrangement? How are the personality, identity, and preferences of the person reflected? Are things done in the person's home that are inappropriate or do not have the person's approval?
- Does the person have the appropriate range of responsibilities such as paying of bills, household chores, home and garden maintenance, relations with neighbours, etc, in their home?
- What other ways is the richness of "home" conveyed in the arrangement?

As one person commented in a survey:

People get their OWN home! A place of their own. A sanctuary. A place to have visitors. A place to grow and develop. A place to have ordinary and everyday experiences. Enjoyment! Personal touches. The desire and dream of most citizens – no more, no less.

Lisa described her living arrangement:

I get to do whatever I want. Even though I get to do what I want, I still have to do the chores.

To what extent is the arrangement truly centred on the person?

The theme "One person at a time" was acknowledged consistently throughout the project as the cornerstone of PRS arrangements. Arrangements that grouped or congregated people with a disability together were perceived to involve ongoing compromises that limited opportunities for the

individual. Congregation was largely seen as meeting the needs of the system rather than the person.

The concept of being “person-centred” or “personalised” is made up of particular criteria that can guide the development of an accommodation support arrangement. These criteria include the following:

- The arrangement is designed around the unique identity of one person. The approach focuses as much on the person’s strengths and capacities as it does on the person’s impairments.
- The person’s “voice” is the primary influence on the development of a PRS. There are many ways in which a voice may be heard, even if normal means of communication are challenged. Often, the person’s voice may be heard through people that know him/her very well.
- PRS arrangements will therefore reflect a wide variety of different living arrangements and lifestyles rather than the “one-size-fits-all” approach which is the tradition of services for people with a disability.
- There is a conscious avoidance of grouping people with a disability together.
- Where grouping occurs, it is not driven by service or agency needs, but may reflect the wishes or preferences of the person with a disability. This principle requires rigorous examination because of the powerful tendency and influence of service planning to be based on grouping.

Luke’s parents expressed the following.

Our thinking was more towards person-centred thinking. More away from, the institution says: ‘this is what we offer. Fit the box.’ We had misgivings and this kind of crystallised them...they perceived that we were being too idealistic holding out for something that really, to make it work for Luke, is going to be extraordinarily difficult for us.

High quality PRS arrangements reflect high quality planning.

Planning is about how decisions are made for the person’s future. These decisions may be about ordinary, day-to-day issues and also decisions that may lead to changes in lifestyle. They can also be about the person’s longer term future. Planning can be formal and involve meetings and written plans. Planning can also be informal and occur around the coffee table.

There are some important considerations in the planning of personalised residential supports for a person with a disability.

- At the heart of a PRS arrangement is keeping the focus on the person so that decisions made involve the person, and the person's interests take precedence over other interests.
- For the person with a developmental disability, the involvement of other people who know the person well and may have a long-term relationship with the person is crucial. Family members particularly have a "natural authority" in most cultures and their involvement is important.
- Planning is often more productive when people in informal relationships with the person are involved, perhaps friends and neighbours, depending upon the purposes of the planning process.
- Planning should be done sooner rather than later – it is never too early to begin a planning process. Sometimes events and needs can move quickly and the lack of a plan can create difficulties. Too often, decisions are made in situations of crisis and this limits the alternatives and even will rule some options out of consideration.
- Planning can take a long-term outlook and anticipate future situations and changes. This is particularly the case as people get older and their needs change.
- Planning will provide an opportunity to consider how the person's interests can be *safeguarded*. It is a good starting point for safeguarding to acknowledge that things will go wrong. If the people who are planning are aware of the person's vulnerabilities, safeguards can be put in place to address them. Safeguards can also identify positive things that are happening in the person's life and ensure they continue.
- Planning can have a cost in terms of time and effort and this should be anticipated and acknowledged.
- Finally, a PRS arrangement can be safeguarded and the person's interests protected by periodically reviewing the arrangement. This can be done formally through a process of external evaluation. It may also be done informally through the involvement of interested people in "keeping an eye on things".

A *Baptistcare* Coordinator commented on Lisa's support network.

She has a huge supportive network. Her grandmother, her great aunty, and there are some other family members who are really interested in Lisa. And Lisa is very forthright and outgoing and will tell you what she wants. There's also Local Area Coordinator involvement. Lisa says, 'this is what I'd like to do, this is where I'd like to go, this is the recreation I'd like to do, this is where I'd like to work.'

Luke's mother described the approach to planning of her son's social support network.

We didn't do it according to the textbook. We did a very organic approach. So Jean (the voluntary network facilitator) invites a few friends she knows who might be

interested in doing something with Luke, and we invite a few of our friends who know Luke, relatives who know Luke, and let's just have a get together every now and then...So it changed over time. It was a very loose sort of thing, but we just kept at it and we kept meeting and we kept going to different things.

A respondent to the surveys wrote:

Firstly, get clear about what needs to be safeguarded. I would suggest that there are things like the person's absolute safety and security, their authority over their home space, their authority over their lifestyle, freely-given relationships, developmental opportunities, having decent, respectful skilled staff, having equal ethical partnering between the individual and the service. Secondly, get clear about what the nightmares would be, such as high turnover of staff, poor service culture, using someone's home for respite or an office base; unequal, unethical power relationships.

Do the person for whom the PRS arrangement is provided and others who are close to him/her have the appropriate degree of control in the arrangement?

Careful consideration must be given to how responsibility and control are worked out in a PRS arrangement. In principle, a PRS arrangement ensures that as much control as is appropriate is held by the person and other people close to the person, such as family members. Often, a PRS arrangement will involve funding and paid service providers and how responsibility and control is shared requires discussion and agreement. What follows are some of the issues that need to be clarified.

- Have the key areas of responsibility and control been identified, e.g., ownership/tenancy arrangements, funding and staffing processes, choices regarding the living environment, others who may share that place, day-to-day matters of living, etc?
- Is there a clear process of discussion and agreement on the key areas of responsibility and control between the relevant stakeholders?
- Are these decisions based on the principle of enabling the maximum feasible degree of responsibility and control being vested in the person and/or others close to the person?
- Where decisions are made by others, is that authority exercised in a manner that is faithful to the person's identity, preferences, and needs?
- Is there an open, trusting relationship between the person, other people close to the person, and formal support providers?

The “natural authority” of parents was acknowledged by a *My Place* Coordinator who conveyed a deep respect for the importance of Andree’s parents in respect to her affairs.

Her parents are very upfront about anything they would want for their daughter. They are very, very supportive of their daughter...They’re very strong advocates. It works really well.

A survey respondent wrote:

A home needs to be crafted with a person, not by others, i.e., the person (and their family) has influence or say over where they live, with whom, and all the design features including how resources are used and all support features.

Is the support that is provided to the person flexible and responsive to the person’s needs and is there a balance between informal and formal supports?

Because the person’s needs and preferences will change over time, a PRS arrangement will be flexible and responsive to those changes. Particular aspects of the arrangements such as funding, direct support, and the residential environment need to be planned as much as possible with this in mind. Having a balance between formal, paid support, and informal support through family, friends, advocates, etc, will contribute greatly to that flexibility and responsiveness. Some important characteristics of support are described below.

- Has consideration been given to the key areas where flexibility and responsiveness are required in the arrangement?
- Is there an awareness of the limitations of formal accommodation support models such as group homes with rostered, paid staff? Often, these approaches lack flexibility and responsiveness to changing needs because of the demands of the service system and the competing needs of other people with a disability who share the arrangements.
- Is funding support individualised and flexible in the face of changing needs and circumstances?
- Have regulations and other formal requirements in the arrangement been minimised? These requirements may limit flexibility and responsiveness.
- Where formal support is required, is the agency involved creative and responsive to the needs of the person? For example, can changes occur in key areas such as the location and type of physical accommodation if required? Can support be flexibly increased or decreased according to the person’s needs?
- How does the arrangement acknowledge, foster, and support informal involvements in the person’s life?

A survey respondent commented on the importance of flexibility.

Whatever is crafted needs to be flexible enough to be changed when a person's desires, needs, or circumstances change. A person should not have to shift just because their needs increase. However, if a person wishes to move, then this is possible (like other citizens).

The role of Vemvane in Rob's life has evolved along with his lifestyle, as the CEO observed.

The fact that when the network is expanded its got its own life. It means we're able to step back as coordinating people. The practical interventions are far less than they were at the start of the co-residency and I think the co-residents could tell you themselves that we interfere very minimally...they are three adults living together, sharing a place. I hope they perceive it that way, but behind it there's still thought, structure, direction, but it's more subtle than it was at the beginning.

A service provider commented:

(Our service) favours freely-given devotions over paid support. Paid supports will always give-way to freely-given devotions and opportunities. This is both cost effective and the best way to promote real friendships.

Does the PRS arrangement provide opportunities for the person's personal growth, including the development of skills and valued roles in the home and the community?

When PRS arrangements are established and operating in line with the expectations of people involved, the person with a disability is often described as "thriving" and generally doing well. These arrangements are associated with a high level of engagement in roles and activities associated with home and opportunities to develop relationships. There is considerable research evidence that positive outcomes are associated with small-scale living arrangements. Some of the developmental outcomes are reflected in the following questions.

- Are well-being and developmental outcomes firmly set as outcomes of the PRS arrangements? Often this will be a primary motivation of families, friends, and service providers in the establishment of the arrangement.
- Are there identified *valued roles* that flow from the PRS arrangement? Is the support necessary to achieve these roles available within the arrangement? These valued roles are potentially plentiful and include such roles as home owner/renter, partner/friend, cook, gardener, decorator, neighbour, valued employee, helper, companion, etc.
- Are there identified *skills* that are developed through the PRS arrangement, with the necessary support to enable this to occur? Such skills are part of household freedoms and

Rob's mother commented on the benefits of her son's co-resident lifestyle.

He doesn't have a disability when he's with them. It's hard to explain. He's got his problems and the rest of it, but I'm sure he feels that he's just one of them. In fact on Saturday night, Ben took him to a gig. He plays in a band and Rob loves it. He loves his music. Give him that any day.

Jackie, in response to what happens with Geoff on the weekends said:

We (usually) stay at home on the weekend here. Geoff can do what we normally do. Help out with the gardening or cleaning. Shopping. A movie. Cooking. Going out...loves a drive. Walking around here often in the evening. Fishing and camping.

Andree's mother summed up Andree's growth and the style of support that has facilitated this.

She's improved heaps. Her development. We thought she'd get to a certain stage and wouldn't improve at all. She's absolutely sort of blossomed basically since she's been in independent living...I think that's the greatest thing in independent living, is that you have a life.

Does the PRS arrangement contribute to the person with a disability participating in the community within a rich and varied network of friends and acquaintances?

Being included means being involved in the life of the person's community through relationships with people. It means spending time physically in the community and participating in what goes on in the community through relationships and activities. Again, valued roles become available through social inclusion. Relationships are the key as the following issues reflect.

- Is there a keen awareness of the importance of relationships for the person, especially those that are close and enduring? How does the PRS arrangement facilitate those relationships?
- Is attention given both to sustaining existing important relationships and also looking out for opportunities for new relationships?
- Valued roles are associated closely with personal relationships. For example, the most valued of roles are associated with being a family member, a friend, a workmate, a partner, etc. These roles are usually reciprocal – the person gives as well as receives in emotional and practical ways.
- Valued roles are also associated closely with participation in a wide variety of activities in the community. These range from being a traveller/commuter, consumer, member, student,

A co-resident named many people in close and long-standing friendships with Rob and also a wide range of acquaintances.

I was always inquisitive of where Rob actually goes during the day, so one day we just jumped in the car and I said 'OK Rob. I want you to take me around to all the places where you go.'...Rob knows his sense of direction really well. He said, 'this is where I go'. We'd go into a shop and people would say, 'hey Robbie! How are you going?', and I introduced myself. 'Hi. I'm Ben. I live with Rob. Just wondering if you ever see him, and it was, 'Oh yeah! Rob comes in a couple of times a day and makes coffee and does this.'...then we go to another little shop in Mt Lawley. There were these girls who work there and they know Robbie as well....It's great to know there's all these people around the place. They know who he is. Everyone sort of looks out for you don't they?

And neighbours are important too.

Neighbours here always make the effort to say 'Hi!' and Geoff is invited with us when they have a barbecue. He gets to know more people through us.

As a survey respondent commented:

Living in one's own home is not enough. All people need company, relationships, friends, neighbours, and to be well connected and valued by their local community and contribute in meaningful ways to the life of the community.

CONCLUSION

This was a fascinating and rewarding project for those of us concerned with it. One conclusion stood apart from the many. It is absolutely possible for people with developmental disabilities, even if their impairments are substantial, to live fulfilling and valued lives, if three ingredients exist:

- The right ideas.
- Leadership to put those ideas into practice.
- The right relationships.

SOME RESOURCES

Community Living British Columbia (2009). *Addressing personal vulnerability through planning*.

<http://www.communitylivingbc.ca/index.htm>

WA Disability Services Commission (2008). *Community Living Plan*.

http://www.disability.wa.gov.au/newsevents/home_news.html?svNews_TYPE=Detail,svMLI_ID=120074

Microboards

In Australia: <http://www.microboard.org.au/page/Home>

In Canada: www.microboard.org

PIN (Planned Individual Networks)

www.pin.org.au

PLAN (Planned Lifetime Advocacy Network)

In Canada: www.plan.ca

WA Disability Services Commission Shared Management Model

http://www.disability.wa.gov.au/dscwr/_assets/main/promotional/documents/doc/smm_brochure.doc

www.supportedliving.org.au